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ABSTRACT

The concept of contact tracing and notification once used for sexually transmitted diseases (STDs) is being mentioned for Acquired Immune Deficiency Syndrome (AIDS). Some professional organizations have supported contact notification; others have opposed it. Initially, states were free to establish their own contact notification programs. More recently, some federally-available AIDS counseling funds require the establishment of contact notification efforts. Consequently, by July 1988, all states encouraged seropositive persons to notify partners. One particularly troublesome trend is the emergence of what might be called "private" contact notification in which an individual with knowledge of the serostatus of another, takes it upon himself to notify a third person of that serostatus. The Acquired Immunodeficiency Syndrome Research and Information Act amendment introduced in April 1988 would deny AIDS research, information, and prevention funds to any state or locality that forbids licensed health care providers from notifying the spouse of a human immune virus-positive person of their potential exposure if the provider believes the infected person will not inform the spouse. AIDS prevention requires reducing high risk behavior. Health promotion and disease prevention stand in contrast to contact tracing. Amendments to federal legislation limiting health promotion efforts targeted to homosexual men are a part of public policy. The experience thus far suggests that political agendas and personal moral philosophies of policy makers have had more to do with the development of AIDS prevention policy than has science. (ABL)

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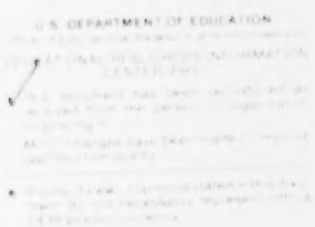

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AIDS, CONTACT NOTIFICATION, AND PUBLIC POLICY

I. Contact Notification--A National Policy

Contact tracing and notification were once considered mainstays of venereal disease control programs. With greater public awareness of the symptoms of STD, much of the treatment and control effort shifted from tracing to reliance on voluntary attendance at STD clinics and other community medical care programs. With the advent of Acquired Immunodeficiency Syndrome, the concept is being dusted off. In its new mantle, it is arousing intense acrimony. Partly, this is due to the intensity of all issues surrounding AIDS. Partly it because the term has such different meanings in different places.

On the one hand, contact notification can conjure up images of forcing people suspected of being in high risk groups to reveal the names of needle sharing or former sexual partners, under penalty of law.

More benignly, it can mean encouraging people who are positive for HIV antibodies to inform sex partners or needle sharing partners that they may be at risk, and to indicate that counseling and testing are available if the partner wishes to seek it out.

The concept of contact notification as a means for reducing the spread of AIDS has elicited strong opinions pro and con. Some professional organizations, such as the Public Interest Directorate of the American Psychological Association, oppose the contact notification, while others, including the American Medical Association, advocate some forms of contact or partner notification.

Some policy makers favor extending one or another variation of the concept to persons with AIDS or positive HIV antibody status on the grounds that contacts should be warned of the life threatening danger they may face, and so that infected contacts can receive information to keep them from unknowingly infecting others.

But some view contact notification as inappropriate for AIDS because, unlike venereal disease, we have no treatment to offer infected individuals; because pressuring counselees to reveal contacts may keep people from visiting counseling sites; because it could destroy the anonymity of testing, since identities of contacts would have to be recorded to locate them, and since contacts would presumably identify the "anonymous" original index case as one of <u>their</u> contacts.

Initially, states were free to determine whether to establish

such programs. More recently, some federally-available AIDS counseling funds require the establishment of contact notification efforts, resulting in the adoption of some form of contact notification virtually everywhere.

The Center for Disease Control currently recommends that persons who are HIV positive be instructed in how to notify their partners and to refer them for counseling and testing. If they are unwilling to notify their partners or if it cannot be assured that their partners will seek counseling, physicians or health department personnel are advised to confidentially notify the partners.[1]

It enforces the recommendation by requiring states to implement sex and needle-sharing partner notification of AIDS patients and HIV seropositive individuals if they seek funding under Cooperative Agreements for AIDS Prevention and Surveillance Projects. It is currently funding 59 programs to conduct partner notification as part of counseling and testing efforts.[2]

Consequently, by July, 1988 the Morbidity and Mortality Weekly Report could report that all states encourage seropositive persons to notify partners, with 48 states, the Virgin Islands, and Puerto Rico offering to notify partners at request of seropositive index person.[3] Some, particularly Illinois, have particularly aggressive laws. That state mandates notification

of all sexual contacts going back seven years, for persons testing positive for the HIV antibody.[4] A referendum to be on California's fall ballot would have similar effect.

Some of the states that pioneered in contact notification programs have reported their results, providing some data on which to base assessments of program effectiveness and cost. We recently undertook an evaluation of New Jersey's nascent contact notification program. As part of our effort to examine the effects of contact notification we conducted preliminary interviews with persons providing AIDS counseling in a number of states with well-developed programs, and examined their reported results.[5]

We were particularly interested in examining the question of coerciveness. The very circumstance, with a government agent appearing unbidden at your door, conveys the message that the state now has you tagged for your sexual behavior or drug usage, and you had better cooperate. In view of these conditions, one would expect a contact notification program to go to great lengths to assure that any agreement to accept counseling or testing be an informed and voluntary one, and not the product of consternation or intimidation. But some of the personnel in counseling and testing sites tell us that contact notifiers have employed fear arousal, guilt, confusion, and aggressive persistence, to elicit cooperation and information from client

informants and from their alleged contacts. For undereducated and uninformed persons unfamiliar with the subtleties of confidentiality laws, and with no reason to trust in the personal integrity of this stranger at the door, these conditions are likely to overwhelm free will.

Reports we have received from some programs raise even more troubling questions of overbearing practices. Workers in Denver, for example, indicated to us that the contact notifier draws blood in the field, during the notification process, if the contact "agrees". This raises serious ethical and legal issues. One of the first legal questions that needs to be raised regarding such practice is whether a battery has been committed where blood is withdrawn under circumstances so intimidating as to taint the putative informed consent. Furthermore, it appears that the contact notifier does not make it entirely clear to the individual being notified and tested in the field that their cooperation is voluntary, that no retaliatory action will be taken if they fail to cooperate, and that his name will be put on a government list if he tests positive.

We were also interested in the reported outcome of existing programs. We found that reports of program outcome often raised more questions than they answered. Colorado is a case in point. Its agencies and legislators have been particularly energetic and enthusiastic about contact notification. The state reports that

between the programs's inception in 1985, and early 1988 370 partners of persons testing positive for HIV antibodies were notified. 100% were reported to have accepted either counseling or both counseling and testing.[6] However, the report does not indicate what "counseling" means in this context. If counselors introduce themselves and state their mission, is this counted as a counseling event even if the door is thereupon slammed in their faces? We don't know, but the question is crucial if we are to have any sense of the program's effect. On the other hand, if 100% of contacts accept real counseling voluntarily, the finding is out of keeping with the controversy that surrounds contact notification programs. The authors of the report themselves, who are employees of the public health agencies, acknowledge an intense and persistent opposition to the state's AIDS control effort.[7] Dr. Vernon of the Colorado Department of Health acknowledges "...consternation, and even outrage in some quarters...".[8] From their reports of the program outcome, however, we must conclude that not even one of these outraged Coloradans fell among the 370 contacts who were notified. Under these circumstances the results should be viewed skeptically until replicated by an independent evaluator.

Even stronger questions arise concerning Idaho's report that all fifty-nine contacts who were located accepted both counseling and testing.[9] With such a powerful effect, one would wish that the evaluator had detailed and documented the content of the

interaction between notifier and contact, both to identify the extraordinarily effective techniques that could explain such an effect, and to assure that improper coercion does not account for the results. Again, the need for an independent evaluation is strongly indicated by such results.

Virginia reported that 59% of 387 individuals testing positive and returning for their results "chose partner referral" as the means to notify their partners.[10] We were surprised that such a large percentage decided against notifying their partners themselves. We called the Virginia sexually transmitted disease program, to confirm this surprisingly high figure. The informant indicated that this includes individuals who notified their own partner in addition to those notified by department personnel. If the informant is correct, the language in the report is misleading, to say the least.

Thus, truly independent evaluations of existing programs are called for. Making policy decisions on the basis of the few state-conducted self evaluations extant appears inappropriate at this time. The information vacuum notwithstanding, contact notification is becoming ever more entrenched in national policy as a major weapon in the battle against the spread of AIDS.

II. "Private" Contact Notification--A Troublesome Trend

One particularly troublesome trend is the emergence of what might be called "private" contact notification. This is the circumstance in which an individual with knowledge of the serostatus of another, takes it upon himself to notify a third person of that serostatus. The issue has usually arisen in the case of a medical provider who identifies a patient as seropositive, and seeks to inform the sexual partner of possible exposure to the presumed etiologic agent of AIDS.

It would seem likely that contact notification has the greatest potential for harm if it is conducted by private persons outside of the rules and controls imposed by the structure of a public agency accountable to the executive, the legislature and the public. Nonetheless, "private" contact notification appears to be approaching entrenchment as national policy.

Under pressure from medical and other groups, some states, most notably California, have weakened confidentiality laws to permit physicians to contact "persons presumed to be" spouses of HIV-positive persons.

Confronted by a lawsuit by a surgeons' association, the New York State Legislature and governor appear on the verge of agreement on a measure that would protect physicians from lawsuits if they notify sex or needle sharing partners of HIV positive individuals that they may have been exposed.[11]

"Private" contact notification is fast becoming national policy. In April 1988, Senator Armstrong of, coincidentally, Colorado, offered an amendment [Amendment Number 1989] to S.1220, the Acquired Immunodeficiency Syndrome Research and Information Act. It was adopted by voice vote.[12]

The amendment would deny AIDS research, information, and prevention funds to any state or locality that forbids licensed health care providers from notifying the spouse of an HIV-positive person of their potential exposure--if the provider believes that the infected person will not inform the spouse. The amendment does not define spouse.

One section could also interfere with health department controls over its own employees.[13] Although unclear and confusing on this point, the section extends the prohibition against policies and regulations as far as health department personnel.

At the minimum, states will be unable to restrict licensed nurses, physicians, physical therapists, chiropractors, dentists, psychologists, optometrists, podiatrists, and the like, from notifying a presumed "spouse" of an HIV-positive individual that they may have been exposed. The likely harm is obvious and manifold. There could be no consistent state policy. Any licensed health care professional would use his or her own standards for

determining who was a "spouse ", for determining whether the HIV-positive person can be believed in agreeing to contact the spouse, and for determining whether it would be harmful to notify the spouse. There could be no required training of notifiers in the skills for sensitive and effective notification; no expectation that the notifier could or would provide appropriate counseling and referral; no check to ascertain that the health provider had correct knowledge about AIDS and its transmission before conducting notifications ; no control over health care professionals with idiosyncratic ideas about AIDS and their own mission; no supervision; no monitoring; no record keeping. It paves the way for exploitation, professional overreaching, perhaps even blackmail.

Why is contact notification so rapidly becoming a centerpiece in the national effort to control AIDS, in the absence of any evidence of its effectiveness; in light of the relatively small numbers of persons who would benefit; and despite its serious harm potential?

It is not entirely clear. There appear to be several pieces to the answer. One is that contact notification presents an image of an aggressive attack on AIDS. Another possibility that cannot be ignored is that contact notification, as opposed to, for example, behavior change programs for high risk individuals, is more popular among some factions because it can be viewed as

protecting "innocents". It appears to address a problem everyone now wants to address. Yet, unlike behavior change programs to assist gay people to adopt safe sex practices, and unlike clean needle programs, it is not subject to the criticism that it panders. Thus, it allows the politician to have it both ways: appearing to do something courageous about AIDS, while not appearing to "promote immorality".

III. Prohibitions on Health Promotion Activities May Facilitate Contact Notification

The substitution of contact tracing programs for less politically popular programs of greater utility is a grave danger, if not a fait accompli.

AIDS prevention requires reducing high risk behavior. Traditional STD tracing has never demonstrated its effectiveness at this. Its historic success has been in getting infected people to accept acute medical treatment for reversible conditions. Health promotion and disease prevention stand in contrast to contact tracing in this regard. Health promotion and disease prevention relate to the kind of efforts that have been developed and tested to help people adopt good health practices. Most of the research has focused on such problems as giving up smoking, taking prescribed medicine, losing weight, and reducing fat in the diet. A substantial body of health promotion literature indicates the

utility, and perhaps necessity, of utilizing the values of individuals at risk, and their cultural context, to effectuate long term positive change in health behaviors.[14] The implications of preventive risk reduction and health promotion literature for AIDS prevention are that information or education programs, and behavior change efforts, are not likely to have a high degree of long-term success unless a broad view is taken of the individual in the context of his total environment, including his personality, subculture, attitudes and belief systems.

While the health promotion literature still guides some AIDS prevention efforts, i.e., those that assist drug addicts to change their needle-sharing behavior, and those that assist heterosexual sex partners of intravenous drug users to adopt safe sex practices, federal funding for health promotion efforts for gay men have been abruptly halted, while notification is becoming the national policy.

The floor amendments to the Senate's AIDS legislation are informative. While forcing states to allow private contact notification described above, the Senate also added prohibitions in two separate amendments against federal assistance for health promotion efforts aimed at promoting safe sex among gay men (amendment numbers 992 and 2700). A hastily-passed amendment to partly undo the effects of amendment number 1992 only goes so far as to permit accurate information on transmission reduction to be

provided to gay men, and does not mollify the effects of that amendment on health promotion programs. Furthermore, amendment number 2700, passed later, would appear to forbid even accurate information to be provided to gay men, if it were to promote or encourage homosexuality, or if it were to use the words "normal", "natural", or "healthy" to describe homosexuality.

Following the first Congressional limitation on health promotion programs for gay men in October, 1987 (it passed 94-2)[15], health departments in Nevada, Illinois, North Carolina, and Delaware have told AIDS service organizations in their states to delete such programs targeted at gay and bisexual men because of the amendment.

The American College Health Association, which receives a federal grant to conduct AIDS education programs on college campuses, has eliminated its more popular and effective materials because of concerns that their explicitness would conflict with the amendment. And the AIDS Clearinghouse no longer distributes health promotion materials targeted at gay and bisexual men for the same reason.[16]

Thus, a program of undemonstrated, even dubious, utility is being entrenched in national policy, while behavior change programs emanating from a substantial body of health promotion and disease prevention research will fade. Although contact notification as a

method of reducing the spread of AIDS is worthy of testing and evaluation, the experiences thus far suggest that political agendas and personal moral philosophies of policy makers have had more to do with the development of AIDS prevention policy than has science.

NOTES

1. Morbidity and Mortality Weekly Report, Volume 37, Number 25; July 1, 1988.

2. 153 Federal Register 3554.

3. Morbidity and Mortality Weekly Report, op. cit.

4. Illinois Laws, P.A. 85-681.

5. Interviews were conducted by Pearl Beck, Ph.D., of the Institute for Health, Health Care Policy, and Aging Research.

6. Morbidity and Mortality Weekly Report, op. cit., p.394.

7. Judson, F.N., and Vernon, T.M., The Impact of AIDS on State and Local Health Departments: Issues and a Few Answers. American Journal of Public Health, Volume 78, Number 4, April, 1988, p.388.

8. Vernon, T. The HIV Epidemic: Colorado's Traditional Approach to Disease Control. AIDS and Public Policy Journal, Volume 2, Number 3, p.34.

9. Morbidity and Mortality Weekly Report, op. cit., p.395.

10. Idem.

11. The New York Times, July 31, 1988, p.1.

12. The Congressional Record, April 28, 1988, S 5029.

13. Section (c) (3) (B) includes in the definition of "physician", "...any person in the state or local government entity's department of health (or comparable agency) who is authorized to act on behalf of any doctor of medicine, nurse practitioner, or other person who provides health care."

14. See Leventhal, Howard, Behavioral Medicine: Psychology in Health Care, in Mechanic, D. (ed.) Handbook of Health, Health Care, and the Health Professions. The Free Press, New York: 1983.

15. The Congressional Record, October 14, 1987, S 14200.

16. The Congressional Record, April 28, 1988, S 5061.